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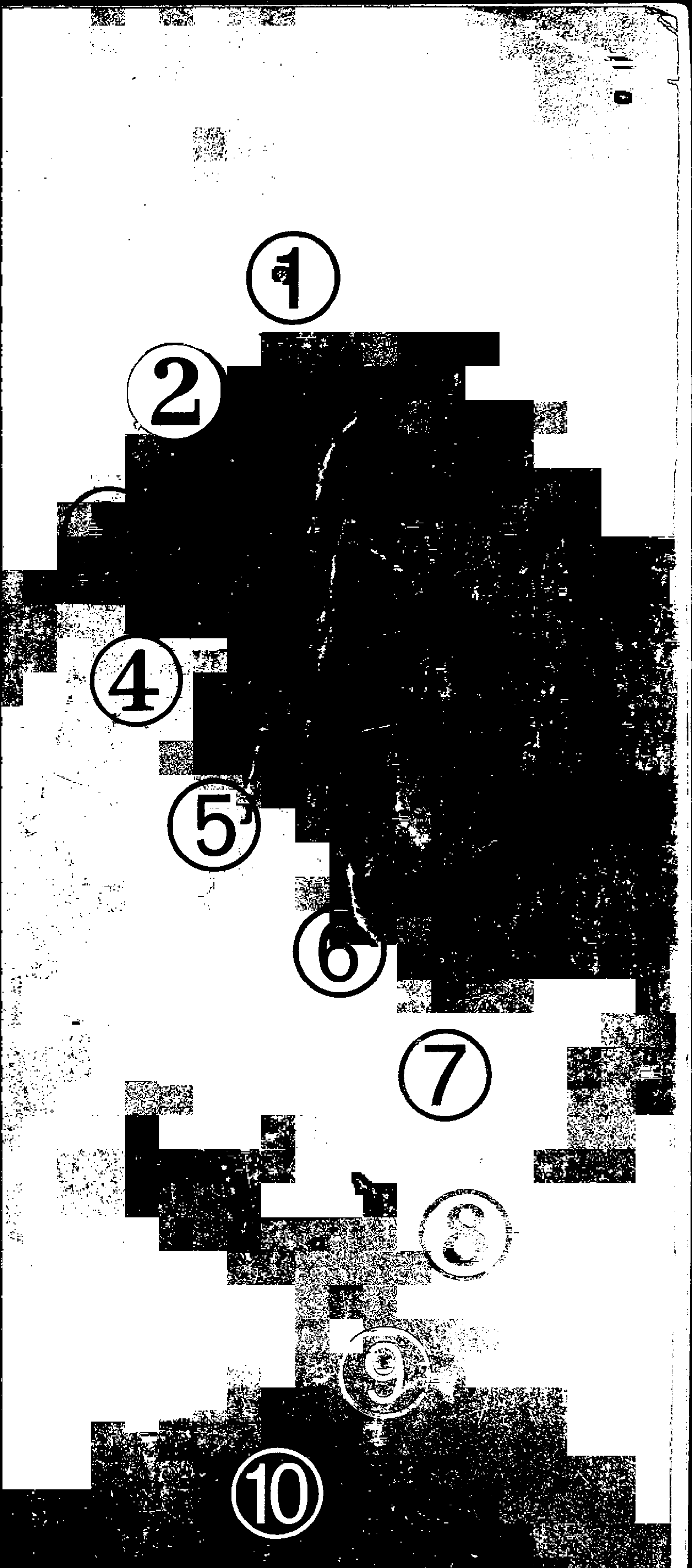
Evidence-Based Patient Choice

Tony Hope



Promoting Patient Choice

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Evidence-Based Patient Choice

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Summary

The report, commissioned by Anglia and Oxford Regional Health Authority, has three aims:

1. to clarify the concept of evidence-based patient choice (EBPC);
2. to provide guidance and make recommendations for the development and funding of future projects in evidence-based patient choice;
3. to describe those projects currently under way within the Anglia and Oxford Regional Health Authority which are centred around evidence-based patient choice.

Its focus is the use of evidence-based information to help people make choices when they, or those close to them, are in need of health care. The report does not address issues to do with the allocation of resources.

The concepts of evidence-based medicine, of patient choice and of the relationships between them are examined and followed by an overview of the various ways in which information can be given and presented to patients. A framework for appraising and developing research on evidence-based patient choice is suggested. The report concludes that EBPC is a coherent concept which brings together two important modern movements within health care. Appendix 1 provides an annotated list of relevant projects and groups within the Anglia and Oxford Regional Health Authority and some key projects elsewhere in Britain. Appendix 2 provides an annotated list of relevant reports.

Introduction

Evidence-based medicine has been described as representing a paradigm shift (Evidence-based Medicine Working Group, 1992). Battista (1993) has described patient centred medicine as a Copernican revolution. The concept of evidence-based patient choice brings together these two important modern movements within health care. Both movements have developed as a critical response to some of the inadequacies of traditional medicine in part as a reaction to what is perceived to be the excessive authority given in traditional medicine to doctors and other health professionals. Evidence-based medicine emphasises the point that it is not the authority of the doctor that justifies a particular clinical intervention but the evidence for the intervention's effectiveness. Patient-centred medicine emphasises the point that patients should play a central role in decisions about their health care. These two ideas have a natural affinity. Providing evidence-based knowledge to patients should enhance their power and aid the development of an increasingly effective patient centred health care.

Chapter 1

Evidence-based medicine

Many people underrate the significance of evidence-based medicine. Like most important new movements it contains, at its heart, a few fundamental tenets. Each of these may in themselves seem obvious, but taken together, and taken seriously, they represent a significant change in the focus of practice.

The fundamental tenets of evidence-based medicine

Davidoff *et al.* (1995) identify five linked ideas as central to evidence-based medicine. They write:

> *'Firstly, clinical decisions should be based on the best available scientific evidence; secondly, the clinical problem – rather than the habits of protocols – should determine the type of evidence to be sought; thirdly, identifying the best evidence means using epidemiological and biostatistical ways of thinking; fourthly, conclusions derived from identifying and critically appraising evidence are useful only if put into action in managing patients or making health care decisions; and, finally, performance should be constantly evaluated.'*

The first and third tenets themselves can be spelt out in more detail as a number of related ideas. First, not all evidence is equivalent. Some types of evidence are much stronger than other types. This may seem obvious but is frequently ignored. It is easy to be influenced, in coming to a decision, not by the strength of evidence but by other factors. Press reports frequently give as much weight to weak evidence as they do to good-quality evidence. Clinicians can be unduly affected by a single personal experience. And when reading scientific and medical journals, the weight given to one point can be influenced more by the number of articles, how recently they were read, and who wrote them, than by the quality of evidence. Second, the strength of evidence can be represented by a hierarchy (see Table 1).

Table 1 A hierarchy of strength of evidence

A systematic review is stronger evidence than unsystematic reviews or single studies.

Systematic reviews where all studies yield similar estimates of the effects of the intervention provide better evidence than when studies yield variable estimates.

There is a hierarchy of study design in terms of the strength they provide, as follows:

1. Randomised controlled trials
2. Non-randomised controlled studies
3. Non-controlled studies
4. Anecdotal studies

In general, evidence-based medicine considers evidence in rather restricted settings: in particular, when the issue is whether an intervention (e.g. a treatment) produces a specific outcome. Types of evidence near the top of the hierarchy (e.g. randomised controlled trials) are better than those lower down in the sense that they rule out more 'spurious' explanations for an association between the intervention and the outcome – that is, explanations which are not causal. Sometimes the benefit of an intervention is so large, and striking, that research designs near the top of the hierarchy are not needed; a randomised controlled trial (RCT) of the effectiveness of blood transfusion in the case of massive blood loss, for example, is both unnecessary and unethical. Various research designs are discussed in detail by Chalmers (1989).

Part of the impetus behind the Cochrane Collaboration, which is an important part of the movement towards evidence-based medicine, is that, by pooling data from many studies, good evidence concerning a particular point may be unearthed that would otherwise be missed.

Not only does evidence-based medicine recognise this hierarchy in the quality of evidence, but it tends to operate a threshold below which evidence is considered so poor as not to be worth considering, in most situations. Only when the clinical situation is such that a decision must be made, and no good evidence exists, should the 'low quality' evidence be used. The Cochrane Collaboration is concerned with systematic reviews of the effects of health care, focusing on RCTs as providing the best available evidence. The NHS Centre for Reviews and Dissemination at York reports the best available evidence, making use of evidence lower in the hierarchy when relevant RCTs are not available. Guyatt *et al.* (1995), in proposing a method for grading health care recommendations, make use of RCTs, cohort studies and case-controlled studies, although explicitly putting considerably more weight on the results of RCTs. It remains unclear, however, and to some extent arbitrary, where the threshold is to be drawn for acceptable evidence. In the context of evidence-based patient choice there is no definitive answer to the question of whether a particular piece of information is 'evidence-based' or not. This point will be taken up later.

An important aspect of evidence-based medicine is that the key questions take origin from clinical situations (Sackett *et al.*, 1991). I will suggest below that in the context of evidence-based patient choice, this point should be extended to emphasise that the questions should take origin from patient's concerns. Indeed, in setting the research agenda for evidence-based patient choice it will be important to collect evidence about patient preferences.

Chapter 2

Patient choice

Informed consent and autonomous authorisation

The philosophical origin of patient choice is the doctrine of informed consent. Informed consent emerged from developments in the law and is informed by philosophical analysis. One central aspect of English (and US) law is that a competent person may refuse (even life-saving) treatment. The choice as to whether to accept or refuse the treatment on offer is a person's clear legal right. For consent, or refusal, to be both legally and ethically valid the person concerned must be given relevant information. If the clinician does not provide information on the broad nature of the intervention, the patient may sue in battery. If the patient is not given sufficient information concerning the risks and benefits of treatment, then he or she may sue in negligence. The general standard for medical negligence is that of the *Bolam* test. As long as a 'responsible body of medical opinion' would support the doctor's action, then that action is not negligent. In English, although not in US, law the same test applies, broadly, to providing information. Thus, in general, the profession sets the standard for the information which should be given at the time consent is obtained.

Developments in medical ethics over the last 20 years have tended to stress the ethical importance of patient autonomy. The principle of autonomy emphasises that patients, by and large, should be in a position to choose whether to accept an intervention or not as part of their general right to determine their own lives. The doctrine of informed consent has, however, been criticised from the perspective of autonomy. The whole idea of 'consent' can be seen as doctor-centred rather than patient-centred. This is because it presumes the model where the doctor proposes the management plan and the patient either does or does not give consent. Faden and Beauchamp (1986) have coined the term 'autonomous authorisation' as a replacement for 'informed consent'. The patient, on their view, should authorise the doctor to carry out some management plan rather than simply consenting to the doctor's proposals. Patient choice goes beyond consent and should involve the patient in the decision-making process. The focus of patient choice is not simply on the provision of information but on the context in which patients are involved in making decisions.

The move towards increasing patient involvement is not driven simply by a theoretical concern for respect for patient autonomy. It is a recognition of the fact that individuals differ both in what they value and in their propensity to take risks. The doctor's yardsticks: 'what would I want if I were in my patient's shoes', or 'what treatment would I want my mother/father etc., to have' do not allow for such individual differences.

Justice and the limits of choice

The principle of autonomy stresses the point that, rather than doctors choosing management plans in the best interests of patients, patients should be enabled to make the choices themselves, or at least clearly delegate this to the doctors. This may, in some instances, conflict with a principle of justice which would demand that the resources available for health care should be used fairly as between different patients. This principle of justice can put limits on patient choice. One patient's preferred choice may not be available because it would prevent other patients from receiving their preferred choices. How conflicting wishes of patients are resolved and who decides, are difficult issues, but the point is that justice demands some limit to unbridled patient choice.

Three components of choice

1. Information

There are three general standards of information which have been proposed in the setting of health care: first, a standard set by the medical profession (which is that adopted by English law); second, the 'prudent patient standard' (which is adopted widely within the USA). This sets the standard as that information which a prudent patient would want to have in order to make a decision about treatment. The courts decide what a 'prudent patient' would want. The third standard is that of the particular patient in the specific setting: that is, the amount of information which the actual patient wants in order to come to a decision. As a legal standard this is problematic, but it is a useful ideal. In particular it emphasises the importance, within a consultation, of each patient being given the opportunity of determining the level, and the kind, of information provided. This ideal has an important implication for evidence-based patient choice. It emphasises that the 'evidence-based information' should be information which patients find of importance in coming to a choice, rather than information which doctors see as important. Doctors and patients will frequently agree on what is important but not always.

2. Education

The purpose of information is to help patients understand their clinical situation and to help them make choices. For both purposes patients need a context in which to understand the information. This is because patient choices, and behaviour, depend not simply on information, but on how that information is understood. I will call this context 'education'. (See below for a full discussion.)

3. Power and involvement

Information and education by themselves are not sufficient. Patients also need to have the power to make choices. One implication of this is that the individual consultation needs to be 'patient-centred' (Stewart *et al.*, 1995; Fulford *et al.*, 1996).

Patient involvement should also extend to involvement in the focus and design of research so as to ensure that the issues for which evidence is sought are issues that are of importance to patients. Oliver (1995) has argued that consumers need to be involved throughout the process of research and evaluation of evidence (see also reports by Oliver listed in Appendix 2). Table 2 lists the checkpoints which Oliver suggests should be applied to both individual trials and reviews. Evidence-based patient choice can be seen as one component of a more general patient empowering movement.

Table 2 Questions to be applied to individual trials and reviews of trials, in order to assess the degree of consumer involvement

1. Was ethical approval given?
2. Was informed consent sought?
3. Were consumers involved in the design of the intervention?
4. Were consumers involved in the design of the evaluation; for instance, did consumers suggest outcome measures?
5. Did researchers collect consumers' views on the intervention?
6. Did researchers collect consumers' views on the evaluation?
7. Were consumers involved in the reviewing process?
8. Were consumers involved in prioritising review topics?

Source: Oliver, S (1995). *Opportunities for highlighting ethics and consumer issues within the Cochrane Database of Systematic Reviews*

Outcome measures

Much research on giving patients information focuses on finding out whether the provision of information is effective. This raises the fundamental issue: effective for what? What are the outcome measures which determine whether the provision of information is successful? Much research uses patient behaviour as an outcome measure and for some purposes this is perfectly appropriate. For example, it is reasonable to ask whether the provision of information on the harmfulness of smoking affects smoking habit. From a public health angle smoking behaviour is an appropriate outcome measure. However, such behaviour change is inappropriate as the key outcome measure in research centred upon patient choice. A central ethical principle behind evidence-based patient choice is that the information is being given in order to enhance choice. The fundamental goal in enhancing choice is to enable each patient to come to his or her autonomous decision, whatever that might be. The goal of enhancing choice cannot be to encourage a specific choice to be made. There can be no ulterior motives, whether to reduce the costs of health care or to persuade people to behave in particular ways, if the goal is to enhance patient choice.

It may, of course, be interesting to see how the provision of particular information does affect choice. Thus, for example, the provision of good quality information on treatments for benign prostatic hypertrophy to patients might, as a matter of fact, lead fewer patients to opt for surgery than if such information is not given. Such an outcome may be seen as desirable on the grounds that it reduces treatment costs, or on the grounds that patients are making better decisions. But these are not the appropriate criteria for whether patient choice has been enhanced.

These considerations raise the difficult issue of what the appropriate outcome measures are by which to judge the enhancement of patient choice. This is an area which requires further conceptual and empirical work. Whatever the exact outcome measures chosen, they will need to focus more on the process by which patients come to a decision, and the extent to which the patient's views determine management, than on what choices are actually made. They might also include whether patients felt they were able to exercise choice, and whether they were satisfied with the decision-making process.

Who is the 'patient' in evidence-based patient choice?

In the standard clinical consultation it is usually clear what is meant by 'the patient'. However, patient-centred medicine and patient empowerment involve a much broader range of situations than that of the consultation. A number of terms has been suggested, including 'consumer' and 'user'. These have been well discussed in Gurney's report, *Public Participation in Health Care* (see Appendix 2).

The term 'evidence-based patient choice' should be restricted to the use of evidence-based information as a way of enhancing people's choices when those people are patients. This does not exclude, however, the provision of evidence-based information to the whole population through the media, or to all school pupils, since that information can then be used by individual people when they are patients. What it does exclude is the use of evidence-based information in determining the allocation of resources, or in deciding on public health programmes. Evidence-based medicine has a great deal to offer in decisions about resource allocation, but this use of its methods is outside the individual patient focus of 'evidence-based patient choice'. One grey area is preventive medicine (e.g. evidence about diet and other aspects of lifestyle). When such information is provided in a clinical setting (e.g. by a general practitioner to a particular patient) it could come under 'patient choice'. When such information is being given as part of a public health campaign to the population in general it is less clear cut. I suggest that such general public health campaigns are excluded from the remit of 'evidence-based patient choice' but I accept that the line of demarcation will not always be clear. There will no doubt be other grey areas, but the core of evidence-based patient choice is in the setting of decisions about individual patients.

Chapter 3

Bringing together evidence-based medicine and patient choice

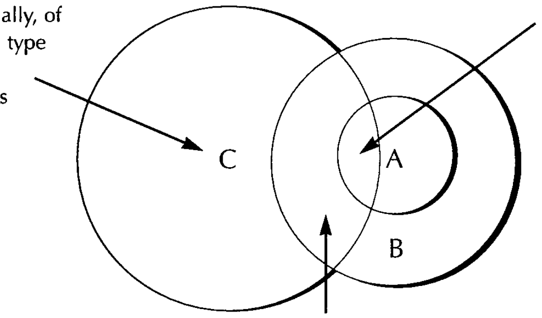
In developing the concept of evidence-based patient choice it is important to clarify how the two halves of the concept relate to each other. I believe that they are synergistic in important and fundamental ways. Because of this, I believe that the concept of evidence-based patient choice is an important and robust one. Each half of the concept brings something of value to the other half. Patient choice is enhanced if patients are given good quality information and the knowledge to discriminate good evidence from bad evidence; evidence-based medicine can be developed by an increasing focus on questions which are important to patients in making choices.

A necessary condition for patient choice is that patients have access to the relevant information. The better the quality of this information, the more autonomous is the choice which is made. Respect for patient autonomy therefore implies that one should strive to improve the quality of the information available to patients. The drive for good quality information, which is at the heart of evidence-based medicine, is therefore fully congruent with one of the key features of patient centred medicine and patient choice. Indeed, respect for autonomy also implies that patients should be given information about uncertainties and gaps in scientific knowledge. Again, one of the contributions of evidence-based medicine is to highlight those issues for which evidence is poor. However, in order for evidence-based medicine to enhance patient choice, it will be important that the scope of the fourth of the 'five linked ideas' (Davidoff *et al.*, 1995 – see above) is enlarged. The conclusions from 'identifying and critically appraising' evidence are useful if they are helpful to *patients* in discussing treatment with their doctors and in making decisions.

Patient autonomy is enhanced, not only by providing good quality information, but also through enabling patients, if they want, to evaluate the quality of evidence. Respecting patient autonomy takes us in the direction of trying to ensure that patients, and the population at large, understand the idea that there are different levels of evidence relevant to health care decisions.

The relationships between evidence-based medicine and patient choice

Figure 1 illustrates the relationships between evidence-based medicine and patient choice, by means of a Venn diagram. Circle C represents information which is of importance to patients in making health care choices. Much of this information is not, even potentially, within the scope of evidence-based medicine. For example, in making decisions, patients often wish to know about the process of health care delivery: what would actually happen if they decided to accept one particular treatment.



Information of importance to patient choice which is not, even potentially, of 'evidence-based' type (e.g. information about the process of delivery of health care)

Area where there is currently good 'evidence-based' information which is of importance to patients in making choices

Information of importance to patient choice which is potentially of 'evidence-based type'

A Information which is currently based on good evidence
B Information for which good quality, evidence-based, information could be available, in due course
C Information which is potentially of importance to patients in making health care choices

Figure 1 The relationships between evidence-based medicine and patient choice

Circle B represents information which comes within the ambit of evidence-based medicine, at least potentially, even if the evidence is not currently available. Not all this information will be significant for patient *choice*. Some information may so clearly show that, given a certain clinical state, there is one best treatment, that there could be no other reasonable choice. In such circumstances the evidence does not so much enhance choice as determine a fixed protocol for treatment. Furthermore, some information may address a question of interest to a research worker, but of no interest to patients.

Circle A represents a subset of circle B, and is that information which is 'evidence-based' and which is currently known. The overlap between circles A and C represents the current position of 'evidence-based patient choice'. The overlap of circles B and C represents what could be achieved.

Increasing the overlap between evidence-based medicine and patient choice

The general aim of a programme in evidence-based medicine should be to enlarge the area of overlap between circles A and C, and to enable patients to use such information in making health care choices.

If good quality information is to enhance patient choice then that information must be about issues which are important to patients in making choices. The implication of this is that patients, and patient representatives, must play an increasing role in the development of evidence-based medicine. Many issues, of course, which are of importance to doctors and scientists are also of importance to patients. However, the perspectives of doctors and of patients are different, and it is these differences which provide much of the impetus for patient-centred care.

Involving patients in evidence-based medicine

Within the framework of evidence-based medicine there are three key places where input from patients is necessary:

- *In choosing the research questions and outcome measures of the primary research studies*. With much of medical research money originating from the population in general (either through government sponsorship or charitable donations), I envisage that there will be increasing involvement of patient representatives in choosing research questions. This is, however, going to take considerable time.

- *In choosing the focus for systematic reviews of good quality trials*. In the context of evidence-based patient choice it is important that the questions chosen are of central importance to patients.

- *In forming conclusions from systematic reviews*. The conclusions reached will depend on the values of the reviewers. The patient's perspective is therefore needed in drawing a conclusion from the review.

Patients' perspectives can differ from those of doctors. For example, benzodiazepines may help women to forget the pain of labour, but also to forget much of the labour itself. While forgetting the pain would normally be desired by mothers, doctors may underestimate the degree to which many mothers want to be able to remember other aspects of the labour.

The patient's perspective may radically alter the conclusions to be drawn from a systematic review. For example, systematic review provides strong evidence that prophylactic antibiotics reduce the frequency of infection following caesarean section. One possible conclusion is that all women should be given prophylactic antibiotics (Sheldon, 1994). However, the base rates for infection in different studies and in different communities are considerable. This raises the question of what the reasons are for these differences, and what can be done to bring the infection rates down to those achieved by the best units. Thus, an alternative conclusion is not that all women should be given prophylactic antibiotics but that great effort should be made to reduce the infection rates in the 'bad' units. In practice, the conclusions and recommendations from a systematic review are likely to determine what changes are made.

Neither conclusion is superior to the other: each represents a perfectly rational response to the data. The conclusions from systematic reviews contain values. From the perspective therefore of patient choice it is important that patients' values are properly incorporated into the conclusions.

Potential biases of good quality evidence

The focus of evidence-based medicine is on high quality evidence. Randomised controlled trials, and systematic reviews of such trials, provide the very best type of evidence. From the focus of the quality of evidence this is perfectly reasonable, but it can introduce certain biases, in the types of information which result, in a direction against the interests of patient choice. For example, randomised controlled trials tend to focus on short-term effects. This is because it is extremely expensive, and takes an enormous length of time, to follow groups prospectively over a long time. This is not to say that RCTs with long-term outcome measures are not possible, and indeed there are examples of such RCTs, but for practical reasons they are relatively rare. On the whole, the best evidence for long-term effects – whether the effects of interventions or long term prognosis – are provided either by cohort studies or by retrospective studies. For example, the best evidence currently available for the long-term unwanted effects of neuroleptic medication in the treatment of schizophrenia comes from retrospective studies (American Psychiatry Association, 1992). Long-term effects are often of major importance to patients in making choices. By focusing on randomised controlled trials a bias against information on long-term effects can be introduced.

The cost of a trial is also affected by the ease with which the outcomes can be measured. Outcome measures which focus on patient's perceptions, experience and mental state functioning, can be more difficult, or more time-consuming, to measure than physiological outcomes. Although RCTs can be carried out with such measures, and indeed many have been, they are relatively few compared with those using more easily assessed outcomes. However, it may be precisely these complex outcomes which are of particular value to patients in making choices.

The Idries Shah effect

Idries Shah tells the story of a man who is searching the street outside his house. A friend walking along the road asks the man what he is looking for. 'I am looking for my key' he replies. His friend helps him search but to no avail. Eventually the friend asks him where he lost his key. 'In my back garden'. In astonishment his friend asks him why he is looking in the street if he lost the key in his garden. 'There is more light out here in the street,' the man replies.

The starting place for evidence-based patient choice must be those questions which are of importance for patient choice, not those questions on which there is the best quality evidence. Evidence-based medicine and the patient centred movement can act synergistically here by encouraging research which uses both good methodology (i.e. provides good quality evidence) and which is designed to answer questions of importance to patients.

Evidence-based recommendations

Recommendations, and protocols, are an important outcome from the application of evidence-based medicine. An excellent example is that of Guyatt *et al.* (1995). Such recommendations can be of benefit to patients because they can improve medical practice. But, specific recommendations can reduce patient choice if they are used in such a way that patients are only offered the one, recommended, choice. For example, Guyatt *et al.* work through the question of whether ranitidine should be administered to seriously ill patients as prophylaxis for gastrointestinal bleeding. Using sophisticated analyses they conclude that such prophylaxis should only be recommended for patients who are not only critically ill but also have a coagulopathy. The calculation involves important value judgements, in particular, the weighing-up of different risks. At root their recommendations are based on the view that those without a coagulopathy are at such low risk of bleeding that it is not worth risking the side-effects of ranitidine. The perspective of patient choice emphasises that patients and their families should be given the opportunity to weigh up these different risks and decide how they wish to balance them. The method of Guyatt *et al.* could be used, however, to enhance patient choice. Their analysis highlights exactly where value judgements come in; and could be used to clarify the effect that altering value judgements should have on the final decision.

Conclusion

It is in the interest of patients to be given good quality information and to understand that different information is based on different qualities of evidence. Evidence-based medicine has therefore a great deal to offer for the enhancement of patient choice. The starting point for evidence-based patient choice should be with issues of central importance to patients. Evidence-based medicine must not unduly restrict patient choice through a dominant concern for identifying the 'best' intervention for each clinical situation. The danger is that only the 'best' option will be available, thus unduly restricting patient choice.

Chapter 4

Information, framing and choice

Any project on evidence-based patient choice will centre around the provision of information in order to enhance patient choice. Several aspects of information need to be taken into account in devising or judging a research project.

What is information?

Most of the literature on providing information to patients takes it for granted that the concept of information is straightforward. Baker and Conner (1994) argue that there are two different approaches to a definition of information. The first is an 'objective' approach. On this view information is independent of the receiver of the information. This is perhaps the common sense view. That World War II began in 1939 would seem to be a piece of information independent of who gives or receives it. The second approach, however, emphasises the importance of the receiver of the information and makes the process of being informed the central concept, rather than the concept of information. On this view something might be information for one person, but not for another, depending on whether the receiver is informed.

The value of this second approach, in the present context, is that it helps to emphasise that the receiver of information must be able to understand and make use of the information. One of the consequences of this, for evidence-based patient choice, is that it emphasises the importance of education to enable the patient to make use of the potential information.

The importance of education

A crude distinction can be made between information (in the relatively objective sense), and education. Education, in this sense, refers to the background knowledge which is necessary for the patient to make good use of the information. It may be necessary, in order for patients to make good use of evidence-based information, that they understand the fundamental idea that there are different qualities of evidence. Without such background knowledge patients are likely to be affected equally by information of very different qualities, and, in the long run, this is likely to undermine the goals of evidence-based patient choice.

In order to make good use of numerical data concerning various possible outcomes it may be desirable for people to understand some of the basic ideas of probability theory (Mazur and Merz, 1994) – the idea of statistical significance, for example. Herxheimer (1995) has emphasised the importance of background knowledge of pharmacology if patients are to be able to make good use of information in coming to a decision about whether and how to take medication.

One implication of this argument is that education may need to be provided along with the information. A leaflet, for example, which gives certain types of information may need also to provide some of this background knowledge; or the doctor may need to give the evidence-based information within a consultation which is centred around the information needs of the patient (Grol *et al.*, 1991).

Information is only one factor important for choice

Patients make choices for all kinds of reasons. Information, and in particular the kind of information which is referred to as evidence-based, is only one type of reason. Jay *et al.* (1987) looked at the reasons why mothers decided to go ahead with circumcision for their baby sons. Mothers largely ignored the physician's information about medical complications. Their decisions were based on social, traditional and religious reasons. In a study of women with breast cancer, Hughes (1993) found that women gave many different reasons for the choices which they made. Mastectomy was chosen by some women on the grounds that they wished not only to minimise the risk of recurrence but also the chance of regretting their choice. Presumably their argument went something like this: 'If I had a lumpectomy and there were a recurrence then I would always think that perhaps I would not have had the recurrence had I had the mastectomy'.

Kelly (1994) interviewed patients offered surgery for ulcerative colitis about the process by which they came to a decision as to whether or not to undergo the surgery. Kelly concluded that those who chose surgery did not weigh up information. Instead, they gradually adapted their view of themselves in such a way as to come to accept the idea of the operation. Kelly likens this process to grieving – a gradual reconciliation to the loss that the surgery represents.

Do patients want information?

One of the forces driving the concept of evidence-based patient choice is the wish to provide patients with information. A key question is whether patients actually want information in the first place. Is the desire to provide information driven by health professionals rather than by patients?

An unsurprising answer is that some patients do want more information, whereas others want limited or even very little information. There is considerable evidence that many patients want more information than they are usually given. Beisecker and Beisecker (1990) found that, on the whole, patients do desire information. They also found that the degree to which patients sought information from their doctors depended, among other things, on how long the consultation lasted. A possible conclusion from this study is that if the time which patients have with doctors is short, then patients will not appear to seek information. It would be easy for doctors to conclude, wrongly, that patients do not want more information. Indeed, Barsevick and Johnson (1990) found only a modest correlation, in women undergoing colposcopy, between those women who wanted more information and those who sought more information. Deber (1994) concluded that in studies with patients with cancer most, but not all, want to be given a considerable quantity of information. This is supported by Sutherland *et al.* (1989). Levenson *et al.* (1982) in a questionnaire survey of patients with cancer found that 35 per cent thought that additional information would have been helpful. Strull *et al.* (1984) found that most clinicians underestimate the amount of information which patients want.

Not all studies show that patients want more information. Broyles *et al.* (1992) found that over half of mothers of newborn babies at risk of respiratory failure wanted only a small amount of information about the procedure and risks of ventilation before giving their consent. They conclude that doctors need to be flexible and sensitive in deciding how much information to give. Since patients vary, one important clinical skill is to gauge how much information a particular patient wants.

Some studies (Neufeld *et al.*, 1993; Hack *et al.*, 1994) have asked patients to characterise themselves with regard to the role they want to take in decision-making. Patients have been helped to do this by choosing from a list of, typically, five different types of role, from: 'I prefer to make the final decision about which treatment I will receive' to 'I prefer to leave all decisions regarding my treatment to my doctor'. The general conclusion is that many, probably most, patients do want considerable information and that doctors tend to underestimate how much information patients want. These issues are discussed in more detail by Entwistle *et al.* (see Appendix 2).

Sometimes patients want information but not choice

There is an important distinction to be made between patients wanting information and patients wanting to make the decisions about which treatment, if any, to have. Several studies have shown that many patients want to be given considerable information, while wanting the doctor to make the final decision about treatment (Blanchard *et al.*, 1988; Beiseker and Beisecker, 1990). For example, Blanchard *et al.* asked a group of cancer patients both whether they would like information and whether they would like to participate in decisions about treatment. Whereas 92 per cent wanted information, 69 per cent wanted to participate in the decision-making process. Twenty-five per cent of those wanting to be given all the information nevertheless wanted the doctor to make the decisions.

Just as there are many things other than information which determine patients' decisions, so patients may wish for information for reasons other than helping them make decisions (Butow *et al.*, 1994). For example, patients often want information about prognosis and process (for example, who will carry out the treatment and where) even when this information will not make any difference to the choices they make.

Does giving information have any effect?

Two kinds of study have been carried out to look at the effects of giving information. One type asks whether information can make a difference to the decisions which patients make; the other asks whether information can have other types of effect (e.g. reducing anxiety).

Tuckett and Williams (1984) reviewed the empirical studies concerned with information giving in medical consultations and conclude that we know very little about the consequences of the exchange of information in the medical consultation. There is some evidence that the giving of information can affect patient choice. Most of this work takes imagined situations. Subjects are asked to say what they would do under certain circumstances. For example, Ainslie and Beisecker (1994) found that a group of elderly people were more likely to choose active treatment, over a range of situations, when given more information. From the perspective of patient choice, it is not necessary to show that information changes the choices that people make. The reason for giving the information is to provide patients with control over their health care; not to manipulate people into making one decision rather than another.

Several studies have demonstrated that giving information can have beneficial effects other than enabling patients to make choices. Caldwell (1991) found that patients who were undergoing surgery and who wanted to be given a great deal of information had lower levels of post-operative stress than passive patients. Morris and Ingham (1988) studied patients with breast cancer for whom there was a choice of treatments. They found that patients who were given a choice did better with regard to measures of psychosocial functioning, and that being given a choice had a greater effect on such functioning than did the type of operation. In a complex study of patients undergoing coronary artery bypass graft operations, Mahler and Kulik (1990) concluded that, on the whole, if patients believe that they have some control over outcomes, then the post-operative morbidity is reduced.

The effect of giving information on the behaviour of patients has also been studied. Lewis *et al.* (1991) designed an education programme consisting of videos and written material and aimed at children, their parents and the paediatric physician. The parents and children took part in this programme while waiting to be seen by the physician. Children who were given this educational programme became more involved in decisions about their health care than those who were not.

The framing of information

The way in which information is presented makes a difference to what people actually do, a fact which is well known to the advertising industry. The implication of this for evidence-based patient choice is that a patient may make a different choice when presented with the same information, but cast in a different form. A simple example: 'this treatment gives you a 5 per cent chance of dying', as compared with, 'this treatment gives you a 95 per cent chance of living'. The first statement is called the 'negative' frame, the second statement is the 'positive' frame. Most of the work on framing has been carried out using hypothetical situations in which subjects are asked to imagine themselves as patients. Marteau (1989) asked people to imagine themselves as doctors advising patients.

The fact of the framing effect raises an interesting conceptual problem. Is it possible to provide information in a neutral and unbiased way, or is bias inevitable? Or put another way: how should information be provided so as to maximise patient choice? One concern is that the framing effect opens up the possibility of manipulating patients – information can be framed in a way calculated to bring about the choice which the doctor wants. There is no simple answer to this problem. My view is, firstly, that where a framing effect is likely to be important, the same information ought to be provided in several different ways, so that patients can be helped to understand the information from a number of different perspectives; and secondly that there must be no intention to manipulate the patient's decision through the choice of frame.

Some general principles emerge from the work on framing. On the whole, when hope is high, people tend to choose the option which gives them the highest chance of getting a good outcome. Thus, if people are given a range of rewards – a gift of money, for example – but there is a trade-off between the amount to be gained and the probability of gaining it, then, if there is a good chance of getting the money people tend to go for less money but a greater chance of winning it. If, however, the chance of winning is low – as in the National Lottery – then people tend to go for a very low probability of winning a large amount rather than a low probability of winning a moderate amount (see O'Connor, 1989).

A similar idea operates in health care decisions. O'Connor (1989) studied the phenomenon of framing with acutely ill cancer patients. She found that people, not surprisingly, trade off adverse effects of treatments and the chance of cure. The results are broadly in line with those found in experiments on lotteries. If the chance of survival is high, patients tend to choose that treatment which gives the highest chance of survival whatever the adverse effects. If however the chance of survival is low, then patients assume what O'Connor calls a 'dying mode': they tend to opt for the treatment with the fewest side-effects. Their thinking seems to be that since they will probably die anyway they wish to minimise unpleasant effects.

Other factors which affect patient choice have been studied. Mazur and Hickan (1990; 1994) have shown that the number of data points given can affect decisions. They studied hypothetical situations in which there is a choice between two treatments, one of which (treatment A) gives a better chance of survival in the short term but the other (treatment B) gives a better chance of survival in the long term. Survival data were then presented by comparing the chance of surviving for each treatment at various time points (such as at one year, three years and five years). When three time points were given, for two of which treatment A was better, half the subjects opted for treatment A. When six data points were given (by giving more intermediate points), for four of which treatment B was better, only 16 per cent of subjects chose treatment A.

The work on framing is important but most of it is based on hypothetical situations. O'Connor's work is an exception. The experience with Huntington's testing, in which more people said that they would take up a test for the gene when this was a hypothetical possibility than took it up when the test was actually available (Quaid *et al.*, 1989) should lead us to be cautious of the results of experiments which look at decision-making in hypothetical situations.

The presentation of numerical data

Much of the information which comes from evidence-based medicine is numerical in form. It concerns issues such as the chances of certain outcomes given certain interventions, whether these are treatments, investigations or screening methods. The issue of the effect of framing of such information on decision-making has already been discussed. But there is a prior issue of how such numerical and probabilistic data can be given to patients in a way which maximises the chance that patients can use the information in making choices.

Many doctors tend to use words (such as 'rare' or 'likely' or 'possible') rather than numbers, to express the probabilities that wanted or unwanted effects will occur. Several studies have asked patients what they understand by these terms, or in hypothetical situations, have studied how people's interpretations of these terms are affected by the nature of the effect which is being considered. Mazur and Merz (1994) have shown that the term 'rare' when applied to the chance of death was interpreted differently from when it was applied to the risk of pneumonia. These authors recommend that doctors use numerical rather than verbal ways of giving probabilities. However, they believe that patients would benefit from education about numerical data.

Four ways of presenting numerical data are considered by Guyatt *et al.* (1995). These are: relative risk; relative risk reduction; absolute risk reduction; and number needed to treat. Little work has been done either on examining what patients think about these different ways or on the effects of these different ways on patient choice. The difference between relative risk and absolute risk is an important one. Consider a situation where a group of patients have some risk of an undesirable effect (stroke after a TIA, or a second heart attack, for example). Suppose that there is a treatment which halves this risk. The relative risk in this situation is 0.5 and this is quite impressive. Suppose however that the risk of the undesired effect is only 1 per cent in untreated patients (and 0.5 per cent in treated patients). The absolute risk reduction is from 0.01 to 0.005, that is a reduction of 0.005 or 1:200. The number needed to treat is the reciprocal of absolute risk reduction and is therefore 200. Another way of thinking of the number needed to treat is that 199 people would need to be given the treatment without benefit for one person to benefit.

Public health versus patient choice

The four ways of presenting numerical data highlight a difference between the perspective of the population (the public health perspective) and the perspective of the individual patient. If there is a large number of people who could benefit from treatment, then the population perspective tends to encourage treatment. Moderately raised blood pressure is an example. Treatment reduces the chance of stroke. A large number of people have a moderately raised blood pressure. Therefore vigorous treatment will prevent a large number of people from having a stroke. The medical profession, wearing its public health hat, feels a drive to treat.

From the perspective of the individual patient things may look rather different. The risk of stroke is not great; and the risk reduction brought about by treatment is only moderate. The patient is therefore faced with a choice between lifelong medication together with a high chance of unpleasant side-effects (e.g. impotence or lethargy) if the drugs are taken, and a slightly increased chance of having a stroke if they are not taken. It seems likely that the patient's choice will be affected by how the doctor presents the information. 'Number needed to treat' tends to emphasise the small chance of individual gain from taking the medication; relative risk highlights the efficiency of the prophylaxis. In either case the patient is likely to be affected by the doctor's own views, and these will be affected by how the research data have been presented to the doctor.

As with framing, there is no clear-cut answer to the question of what the right way is of presenting data. Since no way is without influence perhaps patient choice is best enhanced by presenting data in a variety of ways.

Some routes of presentation

Evidence-based patient choice is concerned with providing patients with information which will help them to make choices about their own health care, or about the care of those close to them. Everyone is potentially a patient. The question arises as to the settings and methods which are most appropriate for the provision of information. These range from informing the public directly through the media, to enabling health care workers to give specific information during the consultation. There is no good reason to focus on only one method. Below is a list of the various routes and methods of presentation available. It is likely to be fruitful for different research projects to focus on different routes, and, indeed one area for creative research is the devising of new routes for informing patients.

Some sources for the presentation of information

- *The media.* Either to the public in general or targeted to specific groups such as ethnic minorities or people with specific problems.

- *Books/booklets for the general public/public libraries.* These are used by the public for health information. Their role could potentially be increased and evidence-based ideas incorporated.

- *School/university education.* It has been argued that there is both information and a knowledge base which is needed in order to make best use of the information. Educational institutions might be best placed for ensuring that people have the necessary knowledge base.

- *Health shops.* Some places, including Milton Keynes, have experimented with 'shops' where people can walk in off the street and be helped to information regarding health matters.

- *Health information services* are now available in all Regions. The public can phone these services in order to obtain health information.

- *Patient representative groups*, such as community health councils, are a source of information for patients.

- *Specific condition groups.* There is a large number of patient groups each of which specialises in a different medical condition. Many of these groups produce written information and answer questions from the public. The quality of the information is variable.

- *The doctor.* There is evidence that patients put great weight on the information which they receive from their own doctor – both their general practitioner and hospital doctor (Bolton and Britain, 1994; Roberts *et al.*, 1993; Lerman *et al.*, 1990; Levenson *et al.*, 1982; Ward *et al.*, 1989). Indeed, most patients consider their doctor to be their most valued source of information (Elliott, 1995). The consultation with the doctor is also the place at which treatment choices are often made. An important way of enhancing evidence-based patient choice is through affecting the way in which doctors consult.

- *Other staff.* Staff, in addition to doctors, can play an important part in promoting evidence-based patient choice both by providing information and by helping patients to clarify their thoughts. Hospital libraries and information officers (Bolton and Brittain, 1994) could be available for patients to enhance evidence-based choice. One general practice has experimented with an information officer available to patients at the surgery (Polkinghorn, 1993).

Some forms of information

- *Spoken word.* Most patients like to be able to speak with a person they trust. It is unlikely that the spoken word will be replaced by other forms of information for most patients. Audio tapes, either prepared or recordings of the consultation, may be a useful addition to speaking with someone directly.

- *Written word.* There is now considerable knowledge and experience with providing patients with written information, particularly in the form of leaflets (Ley, 1988).

- *Video.* Since a large proportion of the population has home videos, prepared information on video might prove a useful medium for the presentation of both specific evidence-based information and the background knowledge base.

- *Interactive video.* Although at present interactive video uses expensive equipment, prices will fall rapidly, and the CD format is likely to be increasingly used. Interactive video provides the possibility for patients to enter data about themselves (e.g. their age) and to be presented with information which is accurate for them. Videos designed to enhance patient choice in a few specific situations have been developed in the USA (Nelson, 1988; Deber, 1994; Kasper *et al.*, 1992) and research on their value is being undertaken in the UK (see under King's Fund in Appendix 1).

- *Internet.* This is potentially a cheap and effective way of distributing information but it is too early to know whether it will be a widely used source by patients for health information.

Chapter 5

Judging and fostering research

The evidence-based patient choice chain

Figure 2 illustrates what are, I believe, the four key ingredients for evidence-based patient choice. A research project proposal in evidence-based patient choice should state the place(s) in this chain which provide the focus for the study. Below, the links in the chain are examined one by one.

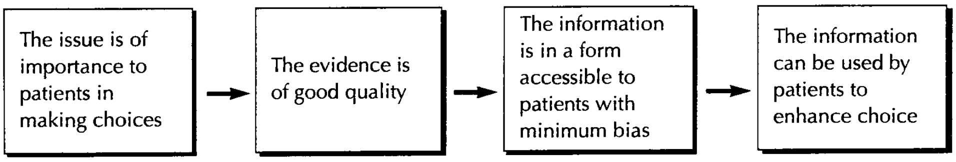


Figure 2 The evidence-based patient choice chain

The issue is of importance to patients in making choices

The starting point for evidence-based patient choice should be an issue which is of importance to patients in making health care choices. Patients need to be involved in identifying these issues. This raises the difficult question of who represents patients. For some research the best representatives may be patient organisations concerned with specific conditions. Other examples of patient representatives are more general patient organisations (e.g. community health councils); and a selection of actual patients. As Sandy Oliver emphasises (see above), patients (or 'consumers') will need to be involved at several points through the research process, for example both in designing, and in choosing, outcome measures (see Table 2), if patient choice is to be maximised.

The evidence must be of good quality

The specific contribution of evidence-based medicine to patient choice is the insistence that evidence is of good quality. The quality of evidence comes in all shades. There is no clear line of demarcation between good quality and poor quality evidence. If the line is drawn too high (for example, allowing only systematic reviews of randomised controlled trials to count as good evidence) then too much information likely to be of interest to patients is excluded. I suggest, for a project to count as evidence-based patient choice, that the evidence should be based on systematic reviews, preferably of RCTs but including systematic reviews of observational studies (cohort and case-controlled studies). This is in accord with the view taken by Guyatt *et al.* (1995) in their discussion of evidence-based recommendations.

Information should be in a form that is accessible to patients with minimum bias

Much of the information which is likely to be the focus of evidence-based patient choice will be complex in nature. Often it will have to do with the probabilities of risks and benefits. Care needs to be taken to ensure that such information is accessible to the majority of patients. It is also important that the information is put across in a way that does not manipulate patient choices. These points have been discussed above. In order to achieve the aims of both accessibility and lack of manipulation, it will often be necessary for the information to be presented in a variety of ways.

The information can be used by patients to enhance choice

Information by itself is not sufficient in order for patients to exercise choice. In order to exercise choice, patients need to have the power to choose. It is therefore critically important, for evidence-based patient choice, that patients are genuinely involved in the process of making health care decisions. This requirement has implications both for the way in which health care services are set up and also for the way in which individual consultations are conducted. An important focus for research into patient choice is on ways for enhancing patients' abilities to make choices.

An eight-point checklist for research protocols in evidence-based patient choice

The evidence-based patient choice chain (Figure 2) can be used as the basis for providing a checklist of points in evaluating research protocols in evidence-based patient choice. This checklist could be used in both evaluating protocols that have been submitted and in helping research workers to prepare a grant application. Not all points in the checklist will be relevant for all studies. Few studies will relate directly to all four links in the research chain. However, all applicants for research in the area of evidence-based patient choice should be able to say which link or links of the chain are the focus of their study, and should be able to address each of the checklist points, if only to explain why a specific point is not relevant to their particular study.

1. Is the information known to be of interest to patients?

What evidence is there that the information which is the focus of the study is information which is of interest to patients in coming to health care choices? The most direct evidence would be that patients, or patients' representatives, were involved, or will be involved, as part of the research, in selecting the information topics and in determining aspects of the research design, such as the choice of outcome measure. Some research in evidence-based patient choice might not involve specific topics of information. For example, a research project could focus on educating health care professionals in providing patients with information on risks and benefits in an accessible form. But such a research project would need to have, as part of its focus, the enabling of health care professionals to find out what information is of interest to patients.

2. Is the information based on good evidence?

This relates to the second link of the research chain. I suggested above that the quality of the evidence should be that recommended by Guyatt *et al.* (1995). The level of the quality of evidence should be chosen to be of as high a quality as is possible given the topic chosen. Those applying for grants should be able to say why they chose the particular level of evidence which they did. Where good evidence of effectiveness is lacking, patients may need to be told this.

3. Is the information, which is provided to patients, in an accessible form?

Applicants should be able to say why they have chosen the particular form in which the information is to be given to patients. Is the form which they have chosen likely to be accessible to most patients?

4. Is the provision of information as free as possible from biases?

While it is not possible to provide information in a totally neutral manner, applicants should be in a position to say what steps they have taken to minimise bias. This would normally include providing the information in a number of different ways.

5. Is the educational base for using the information in place or is it being put in place?

Information is of use to patients only if they have the underlying knowledge to understand and make use of it. Applicants should either be providing this knowledge or should be able to say why they believe that it does not need to be provided.

6. Is it clear that the purpose of providing information is to enhance choice and not to bring about a particular behaviour?

It has been argued above that any research in evidence-based patient choice must take seriously the idea of patient choice. Evidence-based information can be used for other purposes – for example, to encourage patients to choose what is considered to be in their best interests. However, such motivation is at odds with a concern for respecting patient autonomy which is at the centre of the idea of patient choice.

7. Will patients be able to make use of the information in a setting where they can genuinely make choices?

However good the information, and however well presented, it will not, by itself, enhance patient choice if patients do not have the power to choose at the relevant time. If the clinical setting is not the focus of the research, then applicants should be able to suggest the kind of settings in which patients will be able to make use of the information and show that genuine choices will be open to patients.

8. How is the outcome of the intervention to be measured?

One of the most conceptually difficult areas in evidence-based patient choice is measuring the degree of patient choice. It has been argued above that patients' actual choices, while interesting, cannot be the principal outcome measure of how effective an intervention has been in enhancing patient choice. Applicants should normally be able to address the issue of what outcomes would count as a success in enhancing evidence-based patient choice. Such outcomes, I have suggested above, will focus more on the process by which patients come to a decision than on the actual decision itself.

Chapter 6

Conclusions

1. Evidence-based patient choice (EBPC) is a coherent concept bringing together two important modern movements within health care.

2. Research in the area of EBPC must relate to information of interest to patients. It should not simply provide patients with information which is of good quality but is of interest only to health professionals.

3. There is a great deal of expertise within the Anglia and Oxford Region of relevance to EBPC and many ongoing projects (see Appendices 1 and 2). In addition, there are several centres outside the Region which have a major interest in this topic. In particular, the King's Fund Development Centre (London), the Centre for Reviews and Dissemination (York), and the Cochrane Collaboration.

4. Anglia and Oxford Region is well placed to provide a co-ordinated strategy for research within this area.

5. Any research project proposal in EBPC should provide a satisfactory answer to each of the following questions, or should explain why the question is not relevant to the proposed research.

   (i) Is the information known to be of interest to patients?
   (ii) Is the information based on good evidence?
   (iii) Is the information which is provided to patients in an accessible form?
   (iv) Is the provision of information as free from bias as possible?
   (v) Is the educational base for using the information in place, or is it being put in place?
   (vi) Is it clear that the purpose of providing information is to enhance choice, and not to bring about a particular behaviour?
   (vii) Will patients be able to make use of the information in a setting where they can genuinely make choices?
   (viii) How is the outcome of the intervention to be measured?

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Appendix 1

Projects and groups

Patients As Partners Steering Group

A patients as partners steering group has been set up within the NHS and includes members from the NHS Executive, the Department of Health, and patient representative organisations. The Chair is Barbara Stocking, Chief Executive of the Anglia and Oxford Regional Health Authority. Its aims are to produce user involvement in:

- the planning and development of health services;
- the setting of service standards;
- their own health care.

Work to date

Provision of patient information, including the development of the Health Information Services. There has been a particular interest in the provision of good quality (evidence-based) information. The group commissioned the King's Fund to run a seminar at Warwick University on Patient Empowerment (see Appendix 2). A strategy for implementation across the NHS was published in June 1996 following this meeting.

Choices Project

The Choices Project is funded by North Thames Regional Health Authority, and managed by The National Childbirth Trust.

Aims

To determine:

- what women want from their maternity services
- what they have experienced
- the extent to which users were involved in planning services;
- the extent to which users were aware of research evidence, and who used it.

Methods

- Survey questionnaire to all women who gave birth within study frame (Nov–25 Dec 1994), and within the study area (North Essex).
- Focus group discussions.
- User representatives questionnaire.

Outcome

- Data from surveys
- Recommendations, including nine recommendations concerning information and methods of communication.

Consumer Health Information Consortium (CHIC)

A consortium of various health information services. These organisations provided a wide range of information about health and are not, usually, restricted to one disease or group of diseases. Health information services are available in all Regions. Some operate a telephone line only, others include walk-in 'shops'.

Critical Appraisal Skills for Consumers

This project, led by Ruairidh Milne and Sandy Oliver, was funded by the King's Fund Grants Committee. A report was delivered in January 1996.

Aim

To provide the critical appraisal skills programme for members of self-help groups and consumer health information services, to raise awareness of sources of effectiveness data and improve skills in critical appraisal in those who provide information to consumers about health care.

A Pilot Study of Two 'Informed Choice' Leaflets on Positions in Labour and Routine Ultrasound

This project is led by S. Oliver, L. Rajan, H. Turner with A. Oakley at the Social Science Research Unit, University of London Institute of Education.

The Midwives Information and Resource Service (MIDIRS) and the NHS Centre for Reviews and Dissemination (CRD) have developed a set of 'Informed Choice' leaflets for pregnant women and for professionals which they wish to evaluate. These leaflets cover a variety of topics, and each leaflet which has been written for maternity service users is paired with one for health professionals. Each pair of leaflets draws on the same evidence. The role of the Social Science Research Unit has been to work with MIDIRS and CRD in designing, conducting and reporting a pilot study of these leaflets.

King's Fund Development Centre Projects

For the past four years the King's Fund, with additional financial support from the Gatsby Charitable Foundation, has been supporting the evaluation of a series of interactive videos which are designed to provide patients with information about their condition and the risked and benefits of the various treatment options. The videos are the product of The Foundation for Informed Medical Decision Making, an organisation established in the USA by an epidemiologist, Dr John Wennberg. The Foundation was set up to promote the concept of shared decision-making by offering research evidence on treatment outcomes in a way which allows patients to assess the personal risks involved in choices of treatment.

The King's Fund believes that concerted action is required on a number of fronts: research and evaluation; development of new materials; promoting the concept; and exploring commercial potential.

The King's Fund activities, as relevant to EBPC, can be summarised under a number of headings:

1. Evaluation of interactive videos

Two trials of the videos on benign prostatic hyperplasia (BPH) and early breast cancer at Ashford Hospital and the Royal Marsden, initiated by the King's Fund Centre, continue. The BPH video trials, based at the London School of Hygiene and Tropical Medicine, are now funded by the NHS R&D programme. The early breast cancer video trials were funded by BUPA. Two new trials of the US interactive videos began in July 1995. The first, which will use the prostate video and the new videos on benign uterine conditions and hormone replacement therapy in about ten general practices in Oxford and London, is being carried out jointly by the Department of Primary Care and University College London Medical School and the King's Fund. It is funded by the NHS R&D programme. The second trial, funded by the King's Fund, which will also take place in a general practice setting, will evaluate the use of videos on hormone replacement therapy.

The King's Fund continues to promote research and evaluation of materials for evidence-based patient choice.

2. Development of British versions of the US videos

Although the US-produced interactive videos seem to be acceptable to British patients, they would carry more force if they were adapted for a British audience. The King's Fund is also committed to a joint European proposal to produce British, Swedish and Danish versions of at least one of the existing US videos.

3. Development of 'home-grown' materials

A project to produce and evaluate a linear video based on the forthcoming *Effective Health Care Bulletin* on treatment for menorrhagia started in the autumn of 1995. The video is called *Bleeding Nuisance* and will be available in 1998.

The King's Fund has made grants totaling £200,000 to a number of external bodies for the development of materials to promote shared decision-making in the clinical context. These include a multimedia programme and training pack on urge incontinence, audio tapes and booklets for Asian women on the subject of depression, an interactive CD on colorectal cancer, video and leaflets on inflammatory bowel disease, CD-ROM on childhood nocturnal enuresis, and a leaflet, audiotape and video on post operative pain control. Grants were awarded in March 1995 and the work will be completed, in most cases, by the end of 1996.

4. Developing new platforms

During the past year the King's Fund has been exploring the feasibility of producing materials which use cheaper and more accessible technologies than the laser disks used in the US system. The Department of Medical Informatics at University College London Medical School is keen to investigate the feasibility of translating the existing interactive video system to CD-ROM. The Fund has discussed with British Telecom the use of interactive video-on-demand, a dial-up facility using ordinary telephone lines, as a way of making the videos accessible in general practice surgeries or for patients to use in their own homes. The King's Fund is not convinced that interactive technology is the only way to promote EBPC, hence it has decided to encourage the development of materials using more traditional methods, including linear videos, audiotapes and booklets. A report on new technologies relevant to health information will be published as part of this series: *The Future's Bright: The Future's Digital,* by Simon Wallace, and will be available at the end of 1996.

5. Promoting the concept of evidence-based patient choice

The King's Fund has been working with a number of local consumer health information services to strengthen their capacity to respond to enquiries from members of the public about treatment outcomes and alternatives. A survey of local information providers has been carried out, a number of development projects have been funded, and an evaluation report, *Disseminating Treatment Outcomes Information to Consumers*, by Sarah Buckland & Bob Gann, will be published at the end of 1996.

The Fund is planning an international conference in Autumn 1997 which will promote the concept of EBPC and disseminate the results of research in the UK and abroad.

6. Development of a network of people interested in promoting evidence-based patient choice

A network of people interested in EBPC is being established.

Cochrane Collaboration

This is a collaboration between an international network of individuals. The purpose of the collaboration is to prepare, maintain and disseminate systematic reviews of the effects of health care. The reviews focus primarily on randomised controlled trials. There are currently nine centres: UK (Oxford); Nordic (Copenhagen); Italian (Milan), Canadian (McMaster); USA (Baltimore, San Francisco, San Antonio); Australasian (Flinders); Netherlands (Amsterdam). More centres are expected.

There are many 'collaborative review groups' within the Collaboration, each of which focuses on a particular problem. One such group of relevance to EBPC is:

The Effective Professional Practice Group

The contact person is: Emma Harvey, Administrator, Effective Professional Practice Group, The Department of Health Sciences, The University of York, Heslington, York YO1 5DD. Tel: 01904 434 557.

Effective communication with consumers

This review group has not yet registered, but there has been an exploratory meeting.

Consumer Network

Hilda Bastian c/o Australasian Cochrane Centre, Flinders Medical Centre, Bedford Park, SA 5042, Australia. Tel: 0061 (8) 204 8255, Fax 0061 (8) 276 3305. E-mail: cochrane@cc.flinders edu.acc.

The Cochrane Database of Systematic Reviews

A regularly updated electronic journal launched in April 1995. Available from BMJ publishing group (Tel: 0171 383 6185/6245; fax 0171 383 6662) – for IBM PC and AppleMac (disc and CD-ROM)

Getting Research into Practice and Purchasing (GRIPP)

A group of projects with initial funding from NHS Executive. It seeks to explore ways in which purchasers can use research evidence to influence service delivery.

Projects include the following:

1. Glue ear (Nigel McFetridge – Reading)

The aim is to develop, pilot and evaluate the dissemination of evidence-based patient information leaflets and practitioner information leaflets. The hope is that care will be improved by providing this information to patients. Leaflets will be widely distributed to primary and secondary providers within Berkshire Health Authority.

2. Cataract Surgery (Katherine Brogan)

This project is similar to the glue ear project in the overall approach although it focuses on cataract surgery. It will be undertaken in Buckinghamshire Health Authority.

Both these projects are currently at pilot stage, with a view to a future randomised controlled trial. The overall management of these studies is being undertaken by the NHS Centre for Reviews and Dissemination (York).

Health Services Research Group

This is situated at the Institute of Public Health, University of Cambridge, under the direction of Chris Todd. This research institute aims to contribute to better health through the study of population health needs through evaluation of the provision, organisation and delivery of health care. Currently, there are over 20 research projects. Many emphasise the importance of patients' views both on what research should be carried out, and on what should be available.

Some of the main areas of research being carried out are: fracture of neck of femur (e.g. development of measurable targets for quality care); cardiac disease; asthma; road traffic accidents; and palliative care.

The Group's interest in measuring outcomes which are patient-centred is of importance to the idea of EBPC.

A summary of current projects is available in the Health Services Research Group Report, 1994.

CRC Primary Care Education Group

The director of this group is Joan Austoker. The primary interest is in screening. There are several areas of special interest:

1. Breast Cancer Screening

A multi-centre ongoing study looking at both the information being given to patients, and the information which patients want. The study is highlighting the fact that 90 per cent of women being recalled have nothing wrong – i.e. the problem of false positives.

2. Cervical screening

Review carried out of all research on written information for women on screening for cervical cancer. Recommendations made about what should and should not be included in such information.

3. Cancer genetic testing

This project is in the early stages of development. It will focus on women who attend for testing because of strong family history, and will address the problem of how and whether to give women information about likely prognosis when this does not help to improve the outcome.

Milton Keynes Health Shop Survey

This survey is being carried out by Sasha Sheppard and funded by the King's Fund. It involves interviewing people coming into the health shop to find out what it is they want to know.

Medical Risk Studies

This is situated at The Centre for Socio-Legal Studies, Wolfson College and directed by Alex Gatherer.

NHS Centre for Dissemination and Reviews

This centre, situated at the University of York, was commissioned by the Department of Health. The Centre carries out and commissions reviews on aspects of health care. The reviews are systematic and make use of the best information available.

Appendix 2

Annotated list of reports

Consumer Issues in the NHS, by Professor Mildred Blaxter, University of East Anglia, 1995

This was commissioned by the Research and Development Directorate. It looks at the question of the extent to which the concept of 'consumer' is appropriate in the setting of health care; who the 'consumers' are; patient satisfaction; consumer priorities; differences between consumer priorities; differences between consumer and health professional perspectives; and the importance of involving the consumer in research. This report contains about 130 references.

Health Care Partnerships. Debates and strategies for increasing patient involvement in health care and health services, by Christine Farrell and Hilary Gilbert, October 1996

This report of a workshop organised by the King's Fund Centre and the Patient Empowerment Focus Group in April 1995 provides a definition of patient empowerment, and a detailed summary of the conclusions reached. The attitude of health professionals and good quality information for patients were the two most commonly identified factors in the empowerment of individuals.

Choices: An overview of childbirth options, information and care in North Essex, by Meg Gready, Mary Newburn, Rosemary Dodds and Sue Gauge, May 1995

For a summary of the Choices Project see Appendix 1.

Involving Health Service Users in the Implementation of Research Findings: A report to the CRDC Advisory Group on Research Implementation, by Sandy Oliver, Research and Information Group, The National Childbirth Trust, 1994

A report of an informal consultation exercise and a workshop (London, 25 Nov 1994) convened as part of the NHS R&D programme to identify: promising methods for involving users in the implementation process; potential methods for evaluating implementations from a user perspective; and outcomes for measuring the effects of involving users.

Opportunities for Highlighting Ethics and Consumer Issues within the Cochrane Database of Systematic Review, by Sandy Oliver, 1995 (unpublished)

A brief report focusing on a checklist of questions to apply to individual trials and review of trials in order to assess the extend to which consumers have been involved (see Table 2 of this report).

In It Together: Promoting information for shared decision-making, by Jenny Hyatt, July 1994 (commissioned by the King's Fund Development Centre; unpublished)

A report of a review of informational materials used to promote shared decision-making between patients and clinicians in health care. Materials which were reviewed came from five principal sources: self-help and voluntary organisations; health authorities; pharmaceutical companies; health databases; and academic institutions. The report covers: printed; audio; audio-visual; and interactive materials.

The King's Fund Centre developed criteria to determine the extent to which materials were focused on shared decision-making. These criteria included: information should cover all management options including non-intervention; comprehensive and unbiased information should be provided about risks and benefits based on a systematic review of the research evidence; there should be acknowledgment of uncertainties and gaps in scientific knowledge; users and professionals should have been involved in the development and evaluation of materials; materials should be accessible for different user groups; materials should be well designed with simple understandable language; and there should be regular review and updating of the information. Very few materials met all, or even, most, of these criteria.

Oral Health Strategy for the Oxford Region 1993–2002, published by Oxford Regional Health Authority, 1993

One area which this report highlights for the R&D programme is to apply patient-assessed health outcome measures to dentistry (Appendix E of the report).

Disseminating Treatment Outcomes Information to Consumers, by Sarah Buckland and Bob Gann (to be published November 1996)

A report from the Help for Health Trust to the King's Fund, giving an account of a research study. The aim of the study was to assess the extent and nature of the dissemination of information on treatment outcomes by consumer health information (CHI) services in the UK.

A questionnaire was administered to 73 CHI services. Most CHI services deal with treatment outcomes information on a regular basis. Most enquiries are by telephone. Most enquiries are from patients and their carers. Very few enquiries are from self-help groups. Most treatment outcome information enquiries are to do with individual treatments rather than general enquiries. One third of all treatment enquiries were about drug treatments.

The Power of Sharing Knowledge: Consumer participation in the Cochrane Collaboration, by Hilda Bastian, 1994

This report aims to promote consumer participation in the Cochrane Collaboration. It considers the barriers to consumer participation and ways consumers might be involved. An appendix is included on the Cochrane Collaboration/s Consumer Network.

Public Participation in Health Care: Involving the public in health care decision-making: a critical review of the issues and methods, by Ben Hamilton Gurney. A report to the East Anglian Regional Health Authority, Health Services Research Group, University of Cambridge, 1994

The aim of this report was to review and evaluate methods of involving the public in the process by which health care is planned and delivered; and to establish examples of good practice. Its focus therefore is on public participation in purchasing health care. The report includes: a discussion of the terms: 'public participation', 'consultation' and 'involvement'; different groups of 'the public'; a review of some experiments in public involvement in health care purchasing; and, ideas for future research in this area.

Promoting Evidence-Informed Patient Choice and Effective Health Care: A discussion of the issues, by V.A. Entwistle, T.A. Sheldon, A.J. Sowden, I.S. Watt (submitted for publication)

A detailed report on EBPC. It covers, among other topics: a discussion of the pros and cons of encouraging patient choice; the issue of the problem of specifying outcome measures for effective research; a discussion of the various reasons why patient choice might be considered desirable; a review of evidence on whether patients wish to be involved in making decisions; the limits which should be placed on patient choice; ways of presenting information; cultural effects on the presentation of information; and possible priority areas for patient choice. *See also:*

- Evidence-informed patient choice: issues of involving patients in decisions about health care technologies, by V.A. Entwistle, T.A. Sheldon, A.J. Sowden, I.S. Watt. *International Journal of Technology Assessment in Health Care* (in press)

- Supporting consumer involvement in decision making: what constitutes quality in consumer health information?, by V. A. Entwistle, T.A. Sheldon, A.J. Sowden, I.S. Watt. *International Journal for Quality in Health Care* 1996; 8 (in press)

Hospital Users Information Project, by Roger Harrison, published by Milton Keynes Health Authority, 1992

The aim of this project was to assess the quality of information given to hospital inpatients. Most written information had been produced 'in house'. Simple measures for improving the text and layout could greatly enhance the value of much of the information. Several practical suggestions are made.

Health Services Research Group Report, Cambridge 1994

A summary of current research projects undertaken by the Health Services Research Group in Cambridge.

Improving the Quality of the Written Information Sent to Women about Cervical Screening: Evaluation of current letters and leaflets, by Joan Austoker, Claire Davey and Caroline Jansen (in preparation)

A report of a project to assess quality of written information given to women about cervical screening. Written information provided at all stages of the screening procedure was surveyed. One conclusion from the report is that more and better information needs to be provided. The report recommends, among other things, that several topics have been unduly neglected as a focus of research, including the content of reminder letters and describing the validity of the smear test.

Bandolier, edited by Andrew Moore, Muir Gray, Henry McQuay, c/o Pain Relief Unit, The Churchill Hospital, Oxford. Published by the Anglia and Oxford Regional Health Authority from 1994

A monthly 'news-sheet' style journal focusing on evidence-based health care, intended primarily for health care workers. It covers not only health care interventions but also such topics as how to track down copies of an article or book. It is available on the Internet (http: 11www.jr2.ox.ac.uk/Bandolier)

East Anglian Healthline Activity Analysis (April 1993–March 1994), by Margaret Martin and Jane Elliott

Healthline is a consumer health information service based in the NHS regional headquarters at Cambridge. Good records have been kept of enquiries made. This report summarises these records. In one year, 3196 enquiries were made (75 per cent from the public, 70 per cent of which were from women). About 75 per cent of enquiries were about health needs of enquirer or a close relative. Enquiries cover a wide range of issues, the six most common (in order) being: diseases; self-help groups; community services; treatments; hospital services; and waiting times. The main sources of information used were: officers' own knowledge; leaflets; reference directories; and phoning other agencies.

Sources of Health Information for Patients in East Anglia: A manual for general practitioners, by John Polkinhorn, 1993

A comprehensive guide to sources of information. Also includes ideas for ways in which GPs can improve the provision of information to patients, such as a practice having an information officer. This report also gives results of the author's survey of what general practices already did and what they would like to do.

Framework for Public Involvement, by Margaret Martin and Martin Evans. Funded by the East Anglian Regional Health Authority, 1994

A report based on interviews with chief executives of all the health authorities in East Anglia about how the authority involved the public in its planning.

Life in the Slow Lane: The experience of waiting for treatment, by Jane Elliott. Published by Anglia and Oxford Regional Health Authority, 1995

Results of research project involving interviews with doctors, and focus groups with patients, to find out about waiting lists. A number of recommendations are made.

Bridging the Gap, by D. Fenner & I. Pincher. Commissioned by East Anglia RHA in 1993

Report of a research project aiming to identify how health professionals give appropriate information on diseases, conditions and treatments, and to suggest how appropriate health promotion practice can be integrated into all NHS activities. The report focuses on two conditions: coronary heart disease and accidents among under fives. One of the main findings was that the public tend to look to the doctor first for accurate information on health issues – regardless of what doctors themselves or other health professionals wish. There is a problem of access to this information for the public.

But Will It Work, Doctor? edited by M. Dunning and G. Needham. Published by the Consumer Health Information Consortium, 1994

This is a report of a conference. The aim of the conference was to explore ways of making information about the outcomes and effectiveness of treatment and procedures accessible to health care consumers and allowing consumers to influence the research agenda. The report summarises each of the main papers which cover a wide range of aspects central to EBPC.

Consumer Involvement Initiatives in Clinical Audit and Outcome: A review of developments and issues in the identification of good practice, by Marcia Kelson. Published by College of Health. Commissioned by Department of Health, 1995

A detailed and up-to-date review of the subject.

Health Promotion in Primary Care: Physician-patient communication and decision-making about prescription medications, by G. Makoul, P. Arnston and T. Schofield. *Social Sciences and Medicine* 1995; 9:1241–1254

A research report of a study of the observed behaviour of GPs in consultations where new medications were prescribed. The study concludes that the doctors were neither giving nor eliciting much of the information that is likely to help patients in making decisions about their treatment. Patients seldom initiated discussion of such information, and often believed they had received information that was never discussed.

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Evidence-based medicine and patient choice are two of the most significant movements that have recently developed in British health care. In *Evidence-Based Patient Choice* the author argues that both concepts have a natural affinity and can be brought together to enhance the power of patients and help the development of effective patient-centred health care. If patients can be provided with evidence-based knowledge then they can play a central part in decisions about their own health care. *Evidence-Based Patient Choice* combines a rigorous discussion of the ideas and concepts as well as an extensive practical discussion of research and good practice work taking place.

Promoting Patient Choice

The publications in the Promoting Patient Choice series are part of a continuing programme of work within the Clinical Change Programme at the King's Fund Development Centre.
For the past five years, the programme has been promoting concepts and materials which help patients and the wider public to become involved in their own treatment and health care decisions. Government initiatives such as *The Patient's Charter* and *Local Voices* have created major changes in patients' rights and responsibilities and have sought to involve the public in decision-making on a wider scale. The Promoting Patient Choice programme has supported a number of projects, including the use of interactive videos for shared clinical decision-making and a survey of consumer health information services.
Each book in the Promoting Patient Choice series tackles a specific set of issues and is intended to help change and develop professional and public attitudes towards patients' involvement in health care.

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